



COMMONWEALTH of VIRGINIA

Executive Department

Executive Directive 4 (2012)

HEALTH AND HUMAN RESOURCES—ESTABLISHMENT OF A WORK GROUP TO DEVELOP A PLAN FOR IMPLEMENTING A PROGRAM TO SCREEN NEWBORNS FOR CRITICAL CONGENITAL HEART DISEASE

As the chief executive officer for the Commonwealth of Virginia, I hereby issue this Executive Directive to the Executive Branch Cabinet members, agency heads, managers, supervisors, and employees in order to accomplish the goal of screening all newborns in the Commonwealth for critical congenital heart disease. Nothing in this Executive Directive should be construed as imposing an unfunded mandate on any Independent or non-Executive branch agency of the Commonwealth of Virginia.

In Virginia, an average of 3.7 infants per 1,000 live births are diagnosed each year with one of the defects causing critical congenital heart disease. Currently, 74% of newborns are diagnosed at birth. Critical congenital heart disease represents a group of severe and life-threatening clinical outcomes caused by congenital heart defects that result in abnormal blood flow and/or oxygen deprivation. These defects require intervention within the first year of life and delayed diagnosis can result in death or significant morbidity.

Screening newborns for critical congenital heart disease using pulse oximetry has been recommended by the U.S. Department of Health and Human Services Recommended Uniform Screening Panel. Under the leadership of the Commissioner of Health the Virginia Department of Health ("VDH") has already initiated efforts to assess current screening practices and to develop strategies to address the most effective and efficient ways to implement pulse oximetry screening throughout the Commonwealth. While VDH currently administers newborn blood-spot and newborn hearing screening programs, screening for critical congenital heart disease represents a different type and mode of screening that will present unique challenges and barriers.

For this reason, VDH began meeting with key stakeholders in person and by phone in October, 2011. The purpose of these meetings has been to address plans for educating clinicians and communities on new screening standards and on data collection. On November 30, 2011, a federal grant opportunity announcement was posted by the U.S. Health Resources and Services Administration to support the development of a CCHD demonstration project. VDH began working on a grant application in December and submitted its federal grant application for funding to

implement screening for critical congenital heart disease. If the grant is awarded, VDH plans a demonstration project to develop, disseminate and validate screening protocols and to create a statewide newborn screening infrastructure to support point of care screening specific to critical congenital heart disease. The grant project would lead to the creation of a separate subcommittee on the Genetics Advisory Committee to engage stakeholders to provide input and guidance on a statewide plan. The demonstration project would start with one network of birthing hospitals with an eventual phase to add another network of birthing hospitals in the second year before expanding statewide for the third year.

VDH is in the process of preparing a grant application for funding from the Centers for Disease Control and Prevention to fund a statewide conference concerning congenital heart disease in children. This conference will include information regarding the use of pulse oximetry to screen for CCHD.

Establishment of a work group to develop a plan for implementation of a program for screening newborns for critical congenital cyanotic heart disease through the use of pulse oximetry monitoring is of significant importance to the Commonwealth. Accordingly, I direct that:

1. The Secretary of Health and Human Resources, convene a work group, which shall include, but not be limited to, representatives of VDH, the Department of Health Professions, the Virginia Commonwealth University Health System, the University of Virginia Health System, Eastern Virginia Medical School, Inova Fairfax Hospital, Carilion Clinic, the Virginia Hospital and Health Care Association, the Medical Society of Virginia, the American Heart Association, the Virginia Chapter of the American College of Cardiology, the Children's National Medical Center, the March of Dimes Virginia Chapter, and the Virginia Chapter of the American Academy of Pediatrics.
2. The work group shall assist VDH in developing a plan for implementing a program for screening newborns for congenital heart disease using pulse oximetry.
3. The work group shall assist VDH in developing a plan for implementing appropriate early intervention services to newborns identified as having critical congenital heart disease. The goal of early intervention services will be to reduce rates of death or disability among such children.
4. The plan shall include guidelines for implementing the screening program in all hospitals providing maternity services in the Commonwealth, a process for referring newborns identified as having critical congenital heart diseases to appropriate health care services, provisions for public education regarding the symptoms of critical congenital heart disease and options for diagnosis and treatment of this disease, and guidelines for training health care providers regarding the diagnosis and treatment of this disease.
5. The estimated cost of the program and potential funding sources shall be identified in the plan.

6. A report shall be submitted to me by December 1, 2012. This report shall provide an update on the status of the work group. A copy of the report will be provided to the Chairmen of the Senate Education and Health Committee and the House Committee on Health, Welfare and Institutions.



A handwritten signature in black ink, reading "Robert F. McDonnell", written over a horizontal line.

Robert F. McDonnell, Governor

A handwritten signature in blue ink, reading "Janet V. Polarek", written over a horizontal line.

Janet V. Polarek, Secretary of the Commonwealth